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ABSTRACT

This thematic newsletter issue describes programs supporting family members of children with mental, emotional, and behavioral disabilities, as well as the perspectives of family members regarding daily life with these children. The importance of fathers' involvement with a child with special needs and support systems and services that are geared to the father's role and needs are considered. Strategies for involving fathers, stepfathers, grandfathers, uncles, and other significant males in the child's life are discussed. Resources for fathers, including a fathers' network, five publications, and two videos, are identified. Grandparenting roles and the unique relationship of a grandparent with his special needs grandchild are also considered, and a program is described which provides a variety of resources for grandparents, including workshops and support groups, telephone support, and a newsletter. Additionally, programs, services, and considerations regarding siblings of children with special needs are addressed. It is noted that sisters and brothers of a child with special needs can benefit from meeting in a recreational setting with others who have similar experiences. Two organizational resources for siblings, seven books, and newsletters are identified. Personal accounts from five family members are presented. (SW)

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FOCAL POINT

A NATIONAL BULLETIN ON FAMILY SUPPORT & CHILDREN'S MENTAL HEALTH

FATHERS OF CHILDREN WITH SPECIAL NEEDS

Men are increasingly discovering the many joys of active involvement in their children's lives. The special bond between father and child produces measurable, positive effects in regards to a child's self-esteem, gender identity, intellectual growth, curiosity and social skills. Current literature increasingly portrays dads as caretakers, supportive, sensitive and caring. However, this enhanced involvement can be sorely tested when a child has a disability or chronic illness. The dreams fathers have for their child's life, educational, athletic and vocational achievements are threatened.

A man's ability to be an active part of his child's life greatly depends upon his previous learning. Men traditionally have been taught to be providers, problem-solvers, protectors, competitors and controllers. They glory in being self-sufficient, in charge, and strong. A child with special needs often can defeat such roles and render a man depressed, weak, guilty, powerless—and very angry. By default a mother may be conscripted—unwillingly and unwittingly—into being the child's full-time caretaker. Similarly, moms also often become the family's "designated worrier."

Fathers of children with special needs perceive few support systems in their environment; commonly they report feelings of isolation and loneliness. Great strain may be placed upon the marriage and the extended family. A man must push past his denial and develop new paths of involvement in the child's life. He will need to learn appropriate means for communicating and playing with his child who may receive sensory stimulation and movement quite differently than a child who has no disabilities. Further, fathers need places to work through their grief, anger, sorrow and depression.

Professional services generally have been offered during a father's working hours. Mothers—even though often employed outside of the home themselves—often become the resident "expert" about the child's personal, medical and educational needs. Unless the couple has strong, effective communication patterns, the father will likely fall increasingly behind in his knowledge about the child. Parent support programs, while encouraging the involvement of couples, are typically made up of women. The few men who do attend often feel uncomfortable and out of place. The workplace offers little encouragement. Many men find it awkward to share personal concerns with their peers, and a child with special needs just cannot compete with success stories told around the luncheon table.

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GRANDPARENTS & GRANDCHILDREN WITH SPECIAL NEEDS: A UNIQUE RELATIONSHIP

The importance of grandparents in our society is becoming increasingly apparent. The number of grandparents is on the rise due to lengthened lifespans, multiple marriages and increased longevity. With these changes comes a longer period of grandparent/grandchild association and greater potential for grandparents to take on more active roles in the lives of their grandchildren (2, 13, 14, 16, 22, 24, 30). In many respects grandparents—regardless of whether there is a grandchild with a disability in their family—are naturally poised to provide support to their grandchildren. In other contexts, the circumstances of having a grandchild with a disability results in uniquely different family dynamics and perspectives that alternatively define grandparents' role. Moreover, the depth of research regarding grandparents of special needs children is far less than the prevailing literature regarding grandparents in general. Thus our exploration of grandparental support for special needs grandchildren relies on literature that synthesizes information concerning grandparents of children with and without disabilities.

The Evolution of Present Grandparenting Roles. In many respects, expectations regarding grandparenting roles have followed predictable paths. The previous cul-

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We invite our audience to submit letters and comments.

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FATHERS OF CHILDREN WITH SPECIAL NEEDS

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Many men have been taught that feelings are to be hidden. Painful emotions may be camouflaged by addictive behavior (e.g., overwork or abuse of alcohol or other substances) and outward denial ("I'm just fine," "My son is doing great"). Yet, men need to be encouraged to willingly engage in their children's lives in responsible, nurturing ways. In order for this to happen fathers must be given opportunities to explore their feelings in supportive environments.

Many men with special needs children are discovering that they do not need to be limited by stereotypes about what they should be. They have gained increased understanding about the importance of bonding with their children, have accepted the realities of the problems at hand, and become active problem-solvers for their children's needs. Dale Loftis, the father of two children with spina bifida and hydrocephalus states:

We don't have to pretend to be strong. We can admit that life does hurt sometimes, that my child does have some problems, that I have lost that perfect child of my dreams. Having admitted this, I am now free. Free to meet the challenges of tomorrow. Free to be excited about even the smallest progress. Free to make those adjustments necessary to give my son the best family I can give, to be the best dad I can be.

STRATEGIES FOR INVOLVING FATHERS

There needs to be an *attitude and a willingness to involve men* as loving supports for children with disabilities, even when it seems that they are disinterested. The men need not be the children's biological or adoptive fathers; they may be any men who emotionally touch a child's life including stepfathers, grandfathers, uncles, neighbors and friends.

Expect a balance in the family where responsibilities and tasks are shared. Men can advocate for their children, learn how to feed them and understand the various federal and state laws that protect children's rights. Fathers must be given a chance to learn these various skills.

We must provide men with safe settings in which they can identify and *express their feelings*. Unfortunately, many men too often consider their feelings—particularly their fears—as weaknesses. Men whose children have special needs are often flooded with emotion, yet, they may have "tuned-out" and fail to recognize or understand their feelings. Fathers or father figures often hold back their feelings due to a fear of "losing control" or not being understood. They may be afraid that any expression of their true feelings will place even greater strain upon the family. Men require safe settings in which they can grieve the losses associated with having a child with special needs as well as to celebrate their child and family's successes and joys.

It is important to *value the differences* between what fathers and mothers may bring to the parenting setting. For example, perhaps through his employment, the father may have highly-developed skills in navigating

RESOURCES FOR FATHERS

ORGANIZATION: National Fathers' Network
Kindering Center
16120 N.E. Eighth Street
Bellevue, Washington 98008-3937
(206) 747-4004 or (206) 284-2859

WRITTEN MATERIALS:

Circles of Care and Understanding: Support Programs for Fathers of Children With Special Needs (1992). Author: James May, M.A., M.Ed. Available from the Association for the Care of Children's Health, 7910 Woodmont Avenue, Suite 300, Bethesda, Maryland 20814-3015; (301) 654-6549. (Monograph).

Exceptional Parent. Editor: Stanley D. Klein, Ph.D. Includes "Fathers' Voices," a regular column that focuses on fathers' experiences rearing children with special needs. Available from *Exceptional Parent*, P.O. Box 3000, Department EP, Denville, New Jersey 07834; (800) 247-8080. (Magazine).

Fathers of Children With Special Needs: New Horizons (1991). Author: James May, M.A., M.Ed. Available from the Association for the Care of Children's Health (see address and telephone number above). (Monograph).

National Fathers' Network Newsletter. Editor: James May, M.A., M.Ed. Available from National Fathers' Network. (Newsletter).

Uncommon Fathers: Reflections on Raising a Child With a Disability (1995). Editor: Donald J. Meyer. Written by and for fathers whose children have special needs. Available from Woodbine House, Inc., Publisher, 6510 Bells Mill Road, Bethesda, Maryland 20817; (800) 843-7323. (Book).

VIDEOS:

Enhancing Care Delivery for African-American Fathers and Children With Special Needs (In production. Scheduled for completion: December 1995). Producer: James May, M.A., M.Ed. Available from National Fathers' Network.

Special Kids, Special Dads: Fathers of Children With Special Needs (1989). Producer: James May, M.A., M.Ed. Available from National Fathers' Network.

bureaucracies or in construction work. Professionals working with families should promote these differences—encourage the father to take a lead in negotiating the mental health system on behalf of the child and family, or encourage the father to build an adaptive device for his child's special needs.

Let fathers know that it is *okay to make mistakes*—all family members do. Neither fathers nor mothers should feel pressured or embarrassed about their parenting styles. Men need to expand their knowledge about children and actively participate in childrearing. They should be discouraged from settling into the old roles and routines with which they are most comfortable.

Encourage men to *learn nurturing parenting styles*. Many fathers do not have parenting styles that are highly caretaking or self-disclosing—but they can learn. Men need to talk with their own fathers and heal old wounds, finish "old business," and listen to their fathers' stories about growing up. Among others, the writings of Robert Bly, Sam Keen and Kyle Pruett are invaluable in exploring such concerns.

Children deserve the love and support of each of their parents. A key goal for family members and professionals is to promote healing and growth—not isolation and despair. In his novel *The Power and the Glory*, Graham Greene wrote, "[T]here is always one moment...when the door opens and lets the future in." As families and professionals we need to fling open the doors and support fathers in the most loving, supportive means possible.

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James May

BEACH CENTER ON FAMILIES AND DISABILITY EXPLORES FATHER/CHILD RELATIONSHIPS AND THE DELIVERY OF SERVICES TO FATHERS

The Beach Center on Families and Disability is continuing a line of research begun two years ago to increase the responsiveness of service delivery systems to the priorities and preferences of fathers of children who have disabilities. The overall goal of the research is to provide information that will help programs provide family-centered services that are responsive to both mothers and fathers.

The first study conducted by the Beach Center, entitled *Fathers' Relationships With Their Children and Their Perceptions of Those Relationships*, asked fathers of children between the ages of 5 and 9, who did and did not have a disability, to report the time they spent in activities with their children, the types of activities they engaged in with their children and their ratings of their competence and their comfort with their parenting skills. Eighty-six fathers from across the state of Kansas participated in the study.

Results from this investigation indicated that fathers assess their skills as parents similarly and spend similar amounts of time with their children whether they have a child with a disability or not. Fathers whose children have a disability do spend somewhat more time in child care tasks than do fathers whose children do not have a disability, but the differences between the two groups were not significant.

In addition to the specific findings of the research, other trends were noted that were not tested for statistical significance because of the small number of fathers included in the study. Some of these findings include an observation that fathers of children who have disabilities were more likely to engage in activities at home with their children than they were to take the children to activities outside of the home. They also appeared to engage in fewer verbal activities with their children if those children had a disability. Both groups of fathers reported spending a great deal of time watching television with their children. Again, these observations can only be used to suggest further research and study.

A second ongoing study at the Beach Center addressing issues related to fathers of children who have disabilities is entitled *Using Family-Centered Approaches in Providing Services to Fathers of Children in Early Childhood Programs*. In this study, infants and toddlers who have disabilities (Part H) programs, early childhood special education (Part B) programs, Head Start programs, and daycare programs are being surveyed in six states to identify strategies being used to include fathers and other male family members. Fathers will be asked to validate these strategies after they have been identified.

For additional information on either of these studies or on other research conducted at the Beach Center please contact Vicki Turbiville, Ph.D., Project Director, Beach Center on Families and Disability, 3111 Haworth Hall, University of Kansas, Lawrence, Kansas 66045; voice/TDD: (913) 864-7600; fax: (913) 864-7605; E-Mail: beach@dole.lal.ukans.edu. The Beach Center particularly invites fathers who would like to participate as a rater of strategies in the second study to contact the project director.

GRANDPARENTS & GRANDCHILDREN WITH SPECIAL NEEDS: A UNIQUE RELATIONSHIP

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tural roles of grandparents involved their exercise of more power and authority than is currently popular. Current grandparental roles appear to have their greatest effect (directly or indirectly) on the emotional well-being of grandchildren just because the relationship exists (20). While grandparents' roles are likely to vary depending on factors such as the developmental needs of the individual, family dynamics, and family resources (19), control of these roles now are at the discretion of the grandparents and carry much less responsibility (2, 7). In essence, this change in "traditional" roles of grandparenting comes from a different role expectation by society. A norm of "non-interference" has developed, which sanctions against independent grandparental involvement in the lives of their children and grandchildren. Cherlin and Furstenberg (5) noted that this norm was so strong that violating it was considered one of the worst sins that a grandparent could commit. Strom (28) suggested that part of the reason why grandparents were out of touch with their roles as grandparents was that their perspective of what is beneficial to their grandchildren was limited and distant. Past generations of grandparents drew from personal experience and provided relevant information about a society that changed very little. In contrast, society today is far more future-oriented and people tend to often stereotype grandparents' commentary as irrelevant or out of context. Furthermore, grandparents themselves have specific opinions regarding how they desire their roles to be perceived.

Many grandmothers neither like nor fit the traditional image of a cookie-baking homemaker (17). Instead, they emphasized social and recreational functions, preferring short-term, voluntary activities with grandchildren, such as a trip to a museum, that were distinctly different from a parental role (1, 17, 22). Most grandmothers chose interactions that were mutually fulfilling and did not see grandparenting as their most important role in life (17). Grandfathers in the past appeared as passive, distant, and uninvolved family members (7, 16). More recent studies have found grandfathers choosing roles in which they offer grandchildren "wisdom and expertise" over roles in which they are "important but distant" (9, 22).

Johnson (15) suggested three primary factors that influence the contemporary role of grandparent. First, there is a wider structural separation between generations in our culture. Second, there are few strong and explicit expectations of obligations between generations. Third, our society actively encourages personal freedom and independence at the expense of the extended family system. All three of these factors clearly come into play when considering grandparents of children with special needs, but often in uniquely different ways.

Grandparents and Grandchildren With Special Needs

What is the role of the grandparent when a child with a disabling condition is born? According to Berger and Fowles (4) all members of the family experience some form of trauma and all of the family's existing relationships are affected (10, 18, 33). Parents, siblings, and grandparents experience feelings of shock and grief (23, 25, 32). Grandparents experience a double shock of grieving their children's suffering and pain as well as grieving the loss of their expectations of a healthy grandchild (23). In cases where grandchildren have disabilities, grandparents may experience added stress, depression, and ambiguity concerning their roles (14), as well as experience long term adjustment to their "new" role as a grandparent of a child with a disability (25).

Historically, grandparents provide some direct forms of help to grandchildren who do not have disabilities through child care activities like babysitting, providing transportation to and from school, caring for sick children while parents are at work, and even assuming total responsibility in

EDITOR'S NOTE

This issue of our newsletter focuses on traditionally underserved family members of children with mental, emotional or behavioral disabilities. Fathers, siblings and grandparents (as well as aunts, uncles and close family friends) are often invisible players in the mental health services delivery system. These individuals, too, need support as they struggle to cope with a beloved child's disability. We have, perhaps, all been guilty of thinking *first* about a child's mother when we think about the family of a child with a mental health disorder. However, grandparents, siblings and fathers, too, often experience tremendous sorrow about the child they have as well as grieve the loss of the child they had imagined they would have. As do mothers, other family members often feel somehow blamed for the very fact of the child's disability. Families are not blamed for a family member's spina bifida, nor are they blamed for a family member's muscular dystrophy; why, then are they blamed for a family member's mental illness? We must recognize that *all* family members struggle through the search for an accurate diagnosis and the search for appropriate treatment. With these articles we offer suggestions for services targeted to grandparents, fathers and siblings as well as first-person accounts by family members describing their experiences with a child with a mental illness in the family.

cases of child abandonment, parental illness, or death (6, 7, 12, 21). But when there is a grandchild with a disability, grandparents' involvement becomes complicated by the fact that grandparents often lack support to deal with their own grief and have not been provided with the appropriate information and guidance to become as actively involved as they would like (9, 10, 31).

Although research has included grandfathers in some studies their unique role in the family has generally been ignored. A variety of studies have focused solely on grandmothers (1,11,12,14,16,17). Grandmothers have been found to provide direct help by playing the role of family history elder. Activities in this area include teaching family history and tradition, teaching native languages, taking grandchildren to church or synagogue, and giving advice in religious and other matters (1,11, 12,14,16,17).

Mediating Factors for Grandparents' Involvement.

There is widespread agreement in the literature about the importance of geographic proximity and mobility in mediating grandparent/grandchild interactions. Researchers have found that proximity accounts for as much as 62% of the variance in number of visits per year between grandparents and grandchildren (5). Convenient proximity may actually be a necessary but not sufficient factor that serves to create a context in which the relationship can develop (8). Gardner, Scherman, Mobley, Brown, & Scutter (9) proposed that geographic distance was a relevant variable when considering the degree of grandparental involvement with grandchildren with disabilities. Many other studies have also found that the amount of supportive contact increased as distance decreases (11, 22). Conversely, a major cause of lost relationships with grandchildren is thought to be caused by one party moving away (27).

The age of grandparents is another mediating factor. Most researchers agree that grandparenting is mainly a middle-age activity, with levels of contact dropping, especially after age sixty-five (12, 17, 22, 26). The influence of age may be somewhat misleading for another reason as well. Grandparent over 65 years of age are likely to have older children and grandchildren who require less care and attention. Moreover, in the case of grandparents of children with special needs, it is harder to make definitive conclusions regarding the effect of age, because the concept of support is much more functional than hands-on. Thus while it likely that older grandparents of children with disabilities will have less physical contact as their age increases, this

does not preclude their ability and desire to provide emotional or financial support (9, 25).

The effects of ethnicity and gender have also been investigated. There is evidence to suggest that the grandparent role is more salient in some ethnic groups than in the dominant culture in this country (3, 5, 19). Grandmothers did not seem to prefer a particular gender of grandchild in the only study that asked that question (12). However, in a unique study that explored grandchildren's perceptions of the relationship, it was discovered that male and female grandchildren had different desires for the relationship and interacted more with their same-sex grandparents during a crisis (24).

Other than physical barriers such as proximity, the most significant mediating factor for relationships of grandparents with grandchildren who do not have disabilities appears to be the grandparent's relationship with their children and children-in-law (11, 22, 27). Because the grandparent role is often one that is mediated by the grandchild and the parents of the grandchild, it may be contrived and ambiguous (14, 16).

Grandparents who successfully maintain or increase contact with their grandchildren are those who maintain friendly relations with the custodial parents. Successful grandparents tend to maintain a non-judgmental attitude about the disability and make themselves a resource to children and grandchildren (9). Yet it is also important that in developing a friendly, supportive relationship with the custodial parent, grandparents do not "take over" (16), since the adjustment of the grandchild may depend on having supportive, competent parents (21). It may be that the extended family's traditional style of relating to one another is a powerful predictor of grandparent's support.

Implications for Health and Mental Health Personnel.

George (10) recommended a support group that offered a forum to discuss feelings, family communication, and ways by which grandparents can serve as therapeutic agents for grandchildren with disabilities and their nuclear families. Gardner, et al. (9) recommended support programs to empower grandparents as family support providers, by providing them with opportunities to explore their roles, discuss their concerns, obtain desired information, be trained in interactive and open communication techniques, and extend to grandparents specific skills to provide support to their grandchildren in the educational domain. In reality, support programs for grandparents are very seldom available, and the main responsibility for helping grandparents will likely come from the efforts of the individual health professional.

If the professional is unable to create support groups or programs—after evaluating a grandparent's unique needs—the provider will have to function as a manager and direct grandparents toward as many of the appropriate health resources/programs in the surrounding community as possible.

In many cases, it may be helpful for professionals to consider what characterizes very healthy grandparent/grandchild relationships (as well as factors that contribute to poor relationships), and use skill training to foster development in areas that grandparents are amenable to change. One example would be to teach grandparents and parents to openly negotiate their relationships with the grandchild, so that the boundaries, desires, and expectations relating to the child are clearly understood by both generations.

Group training is an intervention that might be useful for grandparents who are interested in potential ways to support their grandchildren. For parents, group training may also be an appropriate way to teach them how to make the most of grandparents' willingness to be involved, without taxing them too much.

Another question pertains to why grandparents appear to effectively foster the grandchild's relationship with the parents, but when it comes to their relationship with their own children they appear less assertive in defining the parameters of this relationship. This phenomenon is further complicated by the fact that grandparents often lack support to deal with their own grief and have not been provided with the appropriate information and guidance to become as actively involved as they would like (10, 25, 31).

Helping professionals are encouraged to explore these variables as they help family members negotiate the grandparent/grandchild relationship. They must be prepared to use skill training to foster development in areas amenable to change, and use supportive tactics in areas of liability.

Conclusion.

Grandparents of children with disabilities have the potential to offer support—not only to their grandchildren—but also to their children. Grandparents express a desire to become more involved in therapeutic and educational interventions targeting their grandchildren. Examples of grandparents' assistance include grandparents visiting and helping with daily activities, spending time with their grandchild, and providing financial support (9, 23). Gardner, et al. (9) described grandparents of grandchildren with disabilities who occupied helping roles. They further reflected that grandparents exhibited a dynamically active interest and commitment to providing support to their children and their grandchildren with disabilities.

The contrast between being a grandparent of a child who has no disabilities versus being a grandparent of a child with disabilities is not clear cut. In our efforts to better understand and predict the roles and support functions that grandparents of special needs children occupy, it is becoming more apparent that a family systems perspective (29) provides one of the more effective perspectives.

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SIBLINGS OF CHILDREN WITH SPECIAL NEEDS
PROGRAMS, SERVICES & CONSIDERATIONS

Brothers and sisters of children with special needs have concerns that in many ways parallel their parents' experience. But compared with their parents, these brothers and sisters enjoy far fewer programs, services and considerations—even though the sibling relationship is frequently the longest lasting relationship in the family. Through research and clinical literature, the concerns of brothers and sisters have been well-documented. The concerns include feelings of loss and isolation when a parent's time and attention is consumed by a sibling's disability or illness. Siblings may feel "left out of the loop" when parents and service providers, wanting to protect them from possible stress, do not share information about a sibling's condition. They may feel isolated if they do not have opportunities to talk with peers who are experiencing similar concerns.

Although they frequently have a life-long need for information about the disability or illness and its implications, siblings have far fewer opportunities for obtaining information than their parents do. Written information about disabilities or chronic illnesses is not often developed for young readers. Should sisters or brothers accompany their parents to a clinic visit or an Individualized Education Program (IEP) or Individualized Family Services Plan (IFSP) meeting, their questions, thoughts or opinions are rarely solicited.

Sibling concerns may include over identification (fearing that they also have the siblings' condition); a perceived pressure to achieve in academics or sports; feelings of guilt about having caused the illness or disability or for being spared the condition; feelings of resentment when the child with special needs becomes the focus of the family's attention or is permitted to engage in behavior unacceptable for other family members; and concerns about their and their sibling's future.

Increasingly, the opportunities many siblings experience by growing up with a brother or sister with special needs are also being acknowledged. These include insight on the human condition; maturity from successfully coping with a siblings' special needs; pride in their siblings' abilities; loyalty toward their siblings and families; and appreciation for their own good health and families.

Creating Programs Specifically for Sisters and Brothers

Like their parents, sisters and brothers appreciate opportunities to meet others who have had similar experiences, dis-

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cussing their common joys and concerns and learning more about issues and services that affect their families. Understanding this, agencies are more frequently creating programs designed specifically for siblings by providing some of the following:

■ To meet other siblings in a relaxed, recreational setting. The chance to meet peers in a casual atmosphere has several benefits. It can help reduce a sibling's sense of isolation. Participants quickly learn that there are others who share the special joys and challenges that they experience. The casual atmosphere and recreational activities promote informal sharing and friendships among participants. The recreational setting helps make the experience rewarding to attend. If a brother or sister regards any service aimed at siblings as yet another time demand associated with the child with special needs, he or she may find it hard to be receptive to the information presented. Sibling events should offer activities that are personally satisfying for the participant, so that he or she is likely to attend in the future.

■ To discuss the joys and concerns common to brothers and sisters of children with special needs. Siblings need opportunities, such as sibling support groups, to network. Through these discussions, siblings may realize that they have many common concerns and experiences. These support systems can help decrease feelings of isolation and provide an opportunity for ongoing support.

■ To learn how others handle situations commonly experienced by siblings of children with special needs. Sisters and brothers of children with special needs routinely face problems that are not experienced by other children. Defending a sibling from name-calling, responding to questions from friends and strangers, and coping with a lack of attention or exceedingly high expectations from parents are only a few of the problems brothers and sisters may experience. Special events for siblings can offer children a broad array of solutions from which to choose.

RESOURCES FOR SIBLINGS

ORGANIZATIONS: **Siblings for Significant Change**
105 East 22nd Street, Room 710
New York, New York 10010
Telephone: (212) 420-0776
Fax: (212) 677-0696

Sibling Support Project
Children's Hospital and Medical Center
4800 Sand Point Way, N.E.
P.O. Box 5371 CL-09
Seattle, Washington 98105-0371
Telephone: (206) 368-4912
Fax: (206) 368-4816

BOOKS:

Binkard, B., Goldberg, M. & Goldberg, P. (1987). *Brothers and Sisters Talk With PACER.* Publisher: Parent Advocacy Coalition for Educational Rights (PACER), 4826 Chicago Avenue South, Minneapolis, Minnesota 55417; (612) 827-2966.

Klein, S.D. & Schleifer, M.J. (1993). *It Isn't Fair! Siblings of Children with Disabilities.* Publisher: Bergin & Garvey, Greenwood Publishing Group, Inc., 88 Post Road, W., Box 5007, Westport, Connecticut 06881; (800) 225-5800.

Lobato, D.J. (1990). *Brothers, Sisters, and Special Needs: Information and Activities for Helping Young Siblings of Children with Chronic Illnesses and Developmental Disabilities.* Publisher: Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, Maryland 21285-0624; (800) 638-3775.

Meyer, D.J. & Vadasy, P.F. (1994). *Sibshops: Workshops for Siblings of Children with Special Needs.* Publisher: Paul H. Brookes Publishing Company.

Meyer, D.J., Vadasy, P.F. & Fewell, R.R. (1985). *Living with a Brother or Sister with Special Needs: A Book for Sibs.* Publisher: University of Washington Press, P.O. Box 50096, Seattle, Washington 98145-5096; (800) 441-4115.

Powell, T.H., & Gallagher, P.A. (1992). *Brothers & Sisters: A Special Part of Exceptional Families.* Baltimore: Paul H. Brookes Publishing Company.

Smieja, L., Thomas, N. & Friesen, B. (1990). *Brothers and Sisters of Children With Disabilities. An Annotated Bibliography.* Publisher: Research and Training Center on Family Support and Children's Mental Health, Portland State University, P.O. Box 751, Portland, Oregon 97207-0751; (503) 725-4175.

NEWSLETTERS:

National Association of Sibling Programs (NASP) Newsletter. Published by the Sibling Support Project, Children's Hospital and Medical Center, P.O. Box 5371 CL-09, Seattle, Washington 98105-0371; telephone: (206) 368-4912; fax: (206) 368-4816.

Sibling Information Network Newsletter. Published by the A.J. Pappenikou Center on Special Education and Rehabilitation, University of Connecticut, 249 Glenbrook Road, Box U-64, Storrs, Connecticut 06269-2064; telephone: (860) 486-4985; fax: (860) 486-5037.

■ To learn more about the implications of their brothers' and sisters' special needs. Sisters and brothers need information to answer their own questions as well as the questions of friends, classmates and strangers. Siblings want to know how the disability or illness may affect their brother or sister's life, schooling and future.

■ To give parents and service providers opportunities to learn more about the common concerns of the siblings. Because parents and service providers often are unaware of the range of sibling issues, activities can be conducted to try to help them better understand "life as a sib." For example, a panel of young adult and adult siblings might relate what they appreciated in their parents' treatment of the children in their families and also what they wish their parents had done differently.

Sibshops

Sibshops, a program developed by the Sibling Support Project, is a national model that offers brothers and sisters of children with special needs peer support and education through workshops as brief as two hours and as long as a weekend. Typical Sibshop workshops are approximately four hours long, usually from 10:00 A.M. to 2:00 P.M. on Saturdays. Generally they are held monthly or bimonthly. During these workshops, information and discussion activities are mixed with lively recreational activities. These might include "New Games" designed to be unique, slightly offbeat, and appealing to a wide range of abilities; cooking; and special guests, who may teach participants mime or juggling. A workshop schedule might look something like this:

■ Trickle-In Activity: Group Juggling
■ Warm-Up Activity: Human Bingo
■ Discussion #1: Strengths and Weaknesses
■ Game: Stand Up!
■ Game: Sightless Sculpture
■ Lunch: Supernachos
■ Game: Push-Pin Soccer
■ Discussion #2: Dear Aunt Blabby
■ Game: Triangle Tag
■ Guest: Mental Health Therapist
■ Closing Activity: Sound Off

Sibling support programs in this model were designed originally for children eight to thirteen years old, but they can be adapted easily for younger or older children.

Including Brothers and Sisters: A Checklist for Agencies.

Here are a few considerations to facilitate the inclusion of siblings in planning and implementing family support services.

■ Are siblings included in the definition of "family?" Many educational and health care agencies have begun to embrace an expansive definition of families (e.g., IFSPs, family-centered care). However, providers may still need to be reminded that there is more to a family than the child with special needs and his or her parents. Organizations that use the word "parent" when "family" or "family member" is more appropriate send a message to sisters, brothers, grandparents and other family members that the organization is not for them. With siblings and primary-caregiver grandparents assuming increasingly active roles in the lives of people with disabilities, we cannot afford to exclude anyone.

■ Does the agency reach out to brothers and sisters? Parents and agency personnel should consider inviting (but not requiring) brothers and sisters to attend informational, IEP, IFSP, and transition planning meetings and clinic visits. Siblings frequently have questions that can be answered by service providers. Brothers and sisters also have informed opinions and perspectives and can make significant contributions to the child's team.

■ Does the agency educate staff about issues facing young and adult brothers and sisters? A sibling panel is a valuable way for staff members to learn more about life as a brother or sister of a person with a disability or chronic illness. Guidelines for panel discussions can be prepared in advance to help facilitate meaningful discussion. Other methods to help educate agency staff include videotapes, books, and newsletters.

■ Does the agency have a program specifically for brothers and sisters? Programs for siblings—preschoolers, school-age children, teens, and adults—are growing in number across the United States. Determine the needs of families served in your local community and develop sibling support programs to meet identified needs.

■ Does the agency have brothers and sisters on the advisory board and policies that reflect the importance of including siblings? Reserving board seats for siblings will give the board a unique and important perspective and indicate the agency's concern for siblings. Developing policy based on the important roles played by brothers and sisters will help assure that their concerns and contributions are a part of the agency's commitment to families.

Summary.

Acknowledging the contributions of brothers and sisters of children with disabilities is an important step toward recognizing the valuable role they play in families. In addition to recognition, siblings need information, support, and the opportunity to be children and to form relationships with other children who have similar experiences.

Donald Meyer

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GRANDPARENTS: THE FORGOTTEN RESOURCE

Project Connect. Project Connect is a program of the Massachusetts Society for the Prevention of Cruelty to Children (MSPCC). MSPCC is a private, non-profit, statewide child welfare agency, dedicated to protecting and promoting the rights and well-being of children. Project Connect is designed to develop, implement and monitor specialized treatment plans for children and adolescents who have severe emotional disorders. Our mission is to provide the creation and coordination of services necessary to keep these children in their own homes, in their own schools, and in their own communities. Project Connect is funded by a grant from the Massachusetts Department of Mental Health and covers an area of twenty-six cities and towns south and west of Boston.

Project Connect's philosophy embraces the core values of the Child and Adolescent Service System Program (CASSP), invites parents to be equal partners in the treatment planning process and focuses on the strengths of the family and the child. As part of our ongoing efforts to make our program more responsive to the needs and concerns of parents, Project Connect sponsored several parent focus groups for the purpose of hearing directly from parents what they though about Project Connect, and discovering what were the significant issues that parents felt affected their goal of obtaining quality services for their child and family. A consultant from Boston's Judge Baker Technical Assistance Center for the Evaluation of Children's Mental Health Systems Change moderated the focus groups. The consultant solicited information in response to a series of open-ended questions that were designed to stimulate people's thinking.

Focus Groups. As it turned out, the major issue addressed in the focus groups was the role that grandparents play in the life of these parents and their children with serious

mental, emotional or behavioral disorders. The discussion was very emotional and seemed to be a topic about which everyone had strong feelings. Responses ranged—on the one hand—to feeling that grandparents play an essential role in helping with the parenting of the child to—on the other hand— expressing a strong desire to keep the parents' and grandchildren's lives completely separate from those of the grandparents due to a belief that involvement with grandparents only created more difficulty and chaos in their lives. Obviously, such definitive and disparate feelings created a lively discussion. What emerged was a clear indication that under certain circumstances grandparents can play a significant role in providing supports to parents who have a child with mental illness. Project Connect has worked over this last year to identify what it takes for this relationship to be a supportive one.

The parents who identified negatively with grandparents' involvement cited three major reasons why it was not helpful: (1) grandparents were not informed, did not understand the nature of the child's disability and therefore were critical and unaccepting, which exacerbated the child's low self-esteem; (2) grandparents were not interested in becoming involved because they did not feel that it was their "job" having already raised their own children; and (3) some parents had difficulty asking their own parents for help as they believed it reflected poorly on their parenting skills, and they did not want to "bother" grandparents enjoying their retirement years.

Most of these parents had never really had an open discussion with their parents about their need for support and about what types of things would be helpful in raising a child with a mental or emotional disorder. Although, in some families, this lack of communication seemed to reflect a long-standing problem between the generations, it was clear that the child's mental illness was the major stressor in many relationships. Because the subject was a source of shame to some and a source of sadness to all, it became one of those issues that families tended to avoid—thereby festering and creating larger problems between the generations.

Like their sons and daughters, grandparents grieved the loss of their idealized grandchild. Even where families recognized and accepted the child's illness, grandparents seemed reluctant to admit that a grandchild was "imperfect." Some grandparents faulted their own child's parenting skills as an explanation for the grandchild's disability—thereby further alienating the generations. The complicated dynamics of parent-child interactions appear to become more pronounced when the focus is on a child who has mental, emotional or behavioral problems.

Other families were extremely appreciative and grateful for the support that they received from their parents in raising a child with severe emotional problems. The ingredients that appeared to make it possible for this to happen were different from family to family, but we did note some common characteristics of relation-

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ships that produced positive intergenerational support.

Parents Provide Clear Information. The first characteristic identified was the parent's ability to give clear directions to the grandparent about the type of help the parent needed from the grandparent. One of the scenarios that we have observed in the course of our work with families is that many times an individual expects someone else in the family to respond to their needs despite the fact that the individual has never directly communicated his or her wishes to the other individual. This is particularly true in parent-child relationships as there is often an expectation that parents will always be able to intuitively identify the needs of their children.

Grandparents' Good Physical and Emotional Health. A second characteristic of positive and supportive families is the grandparent's good physical and emotional health. Individuals who do not feel very positive about their own situation clearly are not able to extend themselves to others. Given their advancing age, this is an important consideration when assessing the level of supportive involvement possible for grandparents on behalf of their children and grandchildren.

Discrete Tasks. Parents identified grandparents as helpful and supportive when their roles and tasks were clearly defined. These parents did not flood or overwhelm grandparents with responsibilities that were too physically or emotionally difficult to handle. More positive results seemed to occur when the grandparents had small defined tasks (i.e., transporting a child to a therapy session) that could be successfully accomplished and completed in a designated period of time. This also helped to lessen the role confusion that occurs in some situations where the grandparent becomes almost a co-parent and the parent loses or relinquishes authority.

Grandparents as Guardians of Family Rituals. We learned, too, that parents believe it is important for grandparents to retain as many of the family's traditional rituals as possible. Thus, while a grandparent may participate in recording behaviors on a behavior chart, that grandparent remains an honored guest at birthday parties and other family celebrations. While grandparents strive to understand the abilities and the limitations of the child with a mental or emotional disorder they are also busy passing on the family's lore.

Grandparents' Understanding of the Child's Disability. A final observation is that parents who were able to educate grandparents about the nature of their child's disorder were more apt to have a productive relationship. What seemed important in this regard was how the education was presented. Generally, like any effort to educate people, it is important to time the intervention when the individual is most receptive to learning. Parents related that they were most effective in educating grandparents closely following an event or situation that the grandparents had observed but did not understand. Therefore, when a six-year-old child with attention deficit hyperactivity disorder (ADHD) behaves impulsively and recklessly at a birthday party, that is a good time to explain the brain's dys-

GRANDPARENT-TO-GRANDPARENT PROGRAM

Minnesota's PACER Center (formally known as the Parent Advocacy Coalition for Educational Rights) launched its Grandparent-to-Grandparent Program in 1991. The goals of the Grandparent-to-Grandparent Program are:

- To support, inform and empower grandparents to act as effective advocates for their grandchildren with special needs;
- To meet other grandparents of children with special needs and share joy, concerns, grief, and common interests;
- To learn helpful strategies that enable grandparents to be helpful to their children and families, and to encourage communication between generations;
- To provide support, both physical and emotional, to their children—the parents of children with disabilities—thus providing and enhancing the grandparenting role; and
- To learn about special programs and services available for children with disabilities and families.

The Grandparent-to-Grandparent Program provides a variety of resources to families including workshops and support groups, telephone support and a grandparent column in PACER's newsletter. The workshops offer grandparents opportunities to discuss the impact of the child's disability on the entire family, and to obtain up-to-date information about the child's special problems and needs. The support group meetings offer grandparents the opportunity to meet other grandparents who share their concerns and experiences.

Experienced and trained grandparents are available to offer mutual support to other grandparents through a telephone support program. These individuals receive training in communication skills, are introduced to community resources and learn procedures for making referrals. The Grandparent-to-Grandparent Program also matches trained grandparents with others wishing ongoing telephone support.

PACER's newsletter includes a grandparents' column. The column serves as a source of information on topics of interest to grandparents and additionally serves as a forum for sharing grandparents' concerns.

For additional information on PACER Center's Grandparent-to-Grandparent Program contact: Jane Johnson, PACER Center, Inc., 4826 Chicago Avenue South, Minneapolis, Minnesota 55417-1098; Voice & TDD: (612) 827-2966; Fax: (612) 827-3065.

function and the role of medication to grandparents.

Treatment Planning Process. From our experience in the treatment planning process, we have discovered that grandparents can play an important role in being part of a natural support system for the parents and child with a mental, emotional or behavioral disability. An initial step at Project Connect is to explore the nature of the parent(s)' and child's relationships with grandparents and other relatives. If there is interest and it is feasible to involve grandparents, we invite grandparents to attend the treatment planning meeting. At this meeting, we include grandparents as an important part of the child's life and solicit their input and ideas about the child's strengths and their help in identifying services they think may be helpful. We always find something in the treatment plan with which the grandparent can help or, if the grandparents are already helping, we formally recognize and encourage their contributions to the family. This meeting also provides an opportunity to offer informal information about the child's disability as it is beneficial to the relationship when grandparents as well as parents start distinguishing between what a child cannot do versus what a child will not do.

Grandparents provide a variety of supports to parents that may appear minimal, yet are very helpful to an overwhelmed parent. We know of instances in which each of the following actions by a grandparent proved very important to a parent: transporting a child to a medical or counseling appointment, taking siblings to various activities, baby-sitting while a parent attends a school meeting, and making dinner during a particularly difficult event (such as a child's hospitalization).

Again, we have found that it is important that the grandparent's role be well-defined, within their capabilities and interests, and something that the parent has identified as being helpful and not intrusive. As with any good treatment planning process, it is necessary to keep in mind that each family is unique and the opportunities for providing support are highly individualized.

One of the best stories about grandparent support came from a retired grandfather who took his eight year old grandson fishing on a regular basis. This child is diagnosed with attention deficit hyperactivity disorder. Amazingly, the child developed the patience to learn to fish despite reports from frustrated teachers that the child was unable to focus on school work.

In summary, our experience has taught us to be aware of the very important role that grandparents can play in the lives of grandchildren with mental, emotional or behavioral disorders and their families. Where possible, our goal is to understand the nature of that relationship and mobilize it as a positive force on behalf of the entire family.

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ONE GRANDMOTHER'S EXPERIENCES

Granddaughter. I have two wonderful grandchildren, Megan, age 21, and her brother Greg, age 24. As a child, Megan was a delicious little one. I remember saying, "Megan, don't ever lose that lovely laugh you have." Her laugh just caught one up—you just enjoyed it—period! I often stayed with the children or they stayed with me when their parents went out of town. I had many opportunities to study Megan and I noticed that her laugh just disappeared.

One day my daughter called and said, "Mother, I've made an appointment to take Megan to see a psychologist." I immediately said, "Oh, I am so relieved." I had been watching Megan and I knew that she was depressed. Something was altering her disposition altogether, but I had not said anything to my daughter as I didn't want to be a meddlesome mother. It may have been easier for me to observe the changes in my granddaughter as I didn't see her every day.

My nursing school education controls my responses to situations. I never panic, but I confess I was very anxious about Megan. I am 88 years old and the oldest of five children. That has a lot to do, too, with the way I respond to crises. I have had multiple family crises fall to me to handle in my lifetime and one just learns to get through them. When I was raising my own children and again with my grandchildren, whenever there is a family crisis, I don't get noisy. I become quieter than ever. I am thinking very, very hard. I think that is always the best move to make in a crisis.

Megan went through a variety of tentative diagnoses. First it was depression and then bipolar disorder. Finally, she received a definite diagnosis of schizophrenia. She has been seeing mental health professionals since the age of 12 and did not receive a definite diagnosis until the age of 15.

For six or seven years multiple crises occurred each and every day. We went from Megan attending a regular high school, to a day treatment program, to her running away from home repeatedly, to her placement in a mental health group home. Finally, my daughter was successful in getting Megan's psychiatrist to place her on clozapine—a medication that has greatly improved my granddaughter's functioning—and now Megan again lives with her parents. Unfortunately, the side effects of

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her medication and Megan's continuing dependence on her parents are a continuing source of stress in the household.

There were two very troubling characteristics about Megan that I had noticed for years. She did not seem to learn from the unpleasant consequences of some of her actions. Megan would always just plunge ahead. It was so difficult to control her. She frequently asked, "Grandma, can we make cookies?" And I always replied, "Yes, but you *have to listen* to my directions because it's the only way we can bake together." Megan's mind does not accumulate information from one occasion to fall back on and use at a later time. We were always repeating. Every baking session with Megan was like the very first session. Years later, after Megan got on the right medication, we learned that she *had* been listening. Her brain had recorded a lot of what she had been taught; she just had not been able to access the information when she needed it.

Another thing I have noticed about my granddaughter is that she doesn't enjoy her own company. She doesn't like being alone. This business of not wanting to be alone is still very dominant today. It causes more difficulties in the family than anything else. What we now know—but had no idea about earlier—is that Megan has heard voices since she was about seven years old. Other people, the television, her Walkman—we think that she used each of these as distractions over the years to avoid the voices. Megan thought everyone heard voices. She had nothing to go on to understand that hearing voices is abnormal.

I am very proud of the fact that Megan got through school. I don't know how she did it given the fact that she was hearing voices. She had a 3.75 grade point average in the sixth grade and now has a modified high school diploma.

Daughter. Fortunately, my daughter and I have always been very close. We have a very good rapport. I cherish the fact that our relationship is very free and easy. My daughter does have down days on occasion and those are of great concern to me because of the tension of the situation. One of the most heartbreaking and discouraging things was watching her struggle for three years to finally get an accurate diagnosis and to obtain services for Megan. We have spent a great deal of time over the years on the telephone, sometimes bawling on both ends, before resolving what the next move would be in this tragedy. I tend to be pragmatic. My daughter called me once in tears before an event and said that Megan had shaved all of the hair off her head. I tried to just get my daughter back on her feet and focus on whether we could get a hat for Megan.

Grandson and Son-In-Law. I've tried to be supportive to my family over the years with whatever was going on at the time. I have shared both in their joys and in their crises. I have tried to carry on whenever something was going on with Megan. For example, my daughter and son-in-law had to take Megan to the emergency room instead of participating in my grandson's 18th birthday family celebration. We just went ahead and went out to dinner. That way my grandson's evening wasn't ruined and his parents could concentrate on Megan.

My support of my son-in-law has really occurred more through the support I give my daughter. I think it is just so much harder for men to accept what is going on in their families. They are so accustomed to making a statement, giving a direction, stating a policy—and they expect that their words will be followed. It is very difficult for men to understand that mental illness cannot be handled that way. The stigma connected to Megan and to her illness seemed to lessen gradually for my son-in-law only after he ran into another well-respected professional in his field at a mental health coalition meeting and learned that this man, too, has a daughter who has schizophrenia.

Friends and Acquaintances. Over the years I confided in one very close friend and told her about Megan's problems. She was quite interested and tried to offer support to me. Recently, I have told several neighbors that my daughter's family has a great tragedy—my granddaughter has schizophrenia. Then I try to tell them something about schizophrenia. It requires a certain self-discipline to not wish to hide Megan's illness.

Hope for the Future. I am an optimist. I always hold out hope that something can be found that will be helpful. I know, too, that as people grow older, often some of the symptoms of schizophrenia diminish. The medication Megan is currently on has been more helpful than we ever dared hope it would be. I am so pleased that mental health researchers are now focusing attention on schizophrenia. I think we can do a great deal to reduce the public's ignorance about mental illness—just note how educated the public has become about so many different types of cancer. Many people do not understand that there is a biological basis for some mental illnesses. I would like to see Megan develop her artistic talents and I look forward to the day when she "enlarges her life" by developing the ability to live apart from her parents.

D.E.L., *Portland, Oregon.*

NEXT ISSUE:

FOCUS ON ADOPTION

The next issue of *FOCAL POINT* will explore the impact of adoption on families. We will examine the particular social and emotional supports adoptees and their adoptive families require. The adoptive family life cycle will be described. The upcoming issue will explore the disproportionate representation of child and adolescent adoptees among youth receiving mental health services. We will discuss the issues presented by transracial and transcultural adoptions.

My Brother James

My brother James is the middle child of two middle class African-American parents. James' life has seemed inconsequential to a variety of people around him. To one of his parents, his development seemed wholly unimportant; to "the mental health system," his life was meaningless and hopeless. His extended and nuclear family members (including my sister Margo and me) were unable to avert a crisis of immense proportions. The professionals who worked with him at a time when—perhaps—something could have been done, did nothing. It has been only as an adult that I have been able to put a face and name to my feelings about this illness from which my brother suffers. James is incapable of functioning within the parameters of normalcy in this society and as such is only marginally able to sustain a quality of life that has meaning. I am sad that—in so many ways— I lost my only brother so early in our lives. I am angry that the systems that were designed to help him did not and in doing nothing helped to destroy his life and our family in the process.

Childhood

It has been eons ago now since James was okay. It was a time of laughter. My brother could make anyone laugh. He was the life of the party. He was always joking about one thing or another. There are many images of him in photo albums with an unmistakably mischievous gesture or face that to this day make my sister and me laugh in fond recollection about the time when things were okay. His musical endeavors also seemed brilliant to me. He would hear a melody one time and within a very short time he would be able to play the tune on our piano. He began trombone lessons in elementary school and I found myself toting both his trombone and my cello on the school bus home while he went to football/baseball/track practices. It was a time when his friends filled our house, his jokes tickled our fancy and his laughter touched our hearts.

I can't remember exactly when things began to change. I guess there were some signs all along. He had very high fevers as a child. I remember watching in terror as my brother, affected by fever, ran around the house looking for his "lightstreamers." At another time, when three frames in our mother's camera had been exposed, none of us would say who did it. My mother spanked all three of us. When the roll was developed, the three exposures were photos of flowers. Finally, my ten-year-old brother confessed. "A voice told me to take the pictures."

Adolescence

By thirteen, like most teenagers, my brother was experiencing a roller coaster of different emotions. He sometimes ran with the "wrong" crowd and he and his "friends" would often "borrow" my mom's car. James found no fulfillment in school or sports or music—all experiences that were, at one time, stimulating. From about that time on, my brother and I did nothing but fight each other. As clearly as I remember the time when he was okay, I also vividly recall some of our battles. I almost always lost. I told my mother and sister that I hated him. I wished that I had a brother who was my friend and not my enemy. By the time my brother was in tenth grade, my mother was confused, frustrated and angry at his behavior. She made arrangements to send him to stay with our father on the East Coast.

Before my brother arrived, my father and stepmother enrolled him in a mostly white military academy. They cited my father's frequent travel leading to his inability to effectively oversee my brother's development, and my stepmother's fear of having to "deal with" James as reasons for the enrollment. Within eight months, my brother was assessed behaviorally disordered (although that probably wasn't exactly what they called it then) by academy psychiatrists and was returned to my father and stepmother. Within one week he was back in Denver with us. His behavior was drastically different. James was withdrawn and often violent. He would sit for hours staring at nothing—at least I saw nothing—or he would spend hours in the bathroom. During the first few months of the manifestation of his illness we were all confused, angry, frustrated and frightened. Was this just the way James was dealing with adolescence or did he in fact have a disease that could be overcome therapeutically? I was skeptical about the diagnosis of mental illness. I believed my brother was just "acting" crazy and did know right from wrong; good from bad. But his "crazy" behavior persisted.

Therapy and Racial Bias

After James returned from the East Coast my parents sought the help of "professionals." My brother regularly saw a child psychologist and the entire family (excluding my father) participated in family therapy. My family's "weaknesses" were analyzed in these sessions. These professionals theorized that without "proper guidance" from a father at home, my brother lacked the paternal support necessary for developing children. They gave James a diagnosis of schizophrenia and started medicating him with lithium and thorazine.

Wade (1993) notes that "several studies have provided support for the contention that racial bias exists in the assessment and diagnosis of mental illness" (p. 541). While I had no "proof" that the child-psychologist and family therapists were biased in diagnosing my brother and providing treatment, my intuitive belief is that this was the case. James was so heavily medicated during this time—and so little time was spent on developing interventions that may have given him skills to cope with the voices and other manifestations of his illness—that there is no doubt in my mind that

assessment and treatment bias exist for children and adults of color.

Family Crisis.

My sister Margo's pregnancy was very exciting news. My mother was ecstatic and I was overjoyed at the prospect of a niece or nephew. My brother just grunted and nodded at the news. As the months wore on, we tiptoed around my brother not knowing what would set him off, not knowing where to turn for help when he got violent, not knowing how to cope. As I recall, it was in the evening when I heard my brother and sister arguing. The threats and arguing got louder. My brother threatened to kill my sister and the baby she was carrying. James kicked my sister's abdomen. My mom called the police. When the police responded, my brother charged at them. James was physically subdued, taken into custody and charged with assault. My sister lost her baby. I was consumed by all of the loss.

The quality of my brother's life changed forever at this juncture. It was at this point in his illness that I began to recognize that the mental health system had wholly failed to address his needs or the needs of his family adequately before it was too late—before James ended up dead, in prison, or in a state mental institution. The mental health system's interventions—before his assault on the police—were not designed to help James and our family cope with the sudden behavior changes. By the time my brother assaulted the police officers, he was already well on his way to being institutionalized in a state hospital. My brother was diagnosed with schizophrenia. A judge ruled that James was incompetent to stand trial for assault and committed him to the Colorado State Hospital in Pueblo where he spent the next seven years.

Mental Health Professionals, Race, Culture and Stress.

Wade (1993) describes the basic methodology of psychiatry as: [C]entered on diagnostic procedure. Understanding of the causation of diagnostic disease involves referring to various explanatory theories. Observations and research findings are usually analyzed by examining the extent to which feelings, behavior, social conditions, etc. deviate from norms or cause distress" (p.542). He goes on to note that "psychiatric categories become stereotypes [and] incorporate the racial stereotypes present in society with little difficulty" (p. 542).

Another researcher noted, "[P]ower and lack of power, inherent in the roles of clinician and client and in their cultural group status, can affect clinical process and outcome" (Pinderhughes, 1989, p. 109).

As I think back to our individual and family therapy sessions, I remember hating to go. It seemed that the issues these researchers described were present in my brother's case. His psychologist never seemed interested in giving us strategies to cope with the disruption and James' delusions but, rather, was more interested in classifying him with schizophrenia and recommending drug therapies. Once my brother was involved with the "helping" systems he was constantly on medication with little or no other intervention. Is this what our society offers people who cannot cope (through no fault of their own) with life's stresses?

WHY NOT?

Families of children or adolescents with emotional or behavioral disabilities are faced with demands that are often incomprehensible to families who have not had to cope with this situation. For these families, much of the time and money that is available is needed for the care and maintenance of the child with the disability. Parents—generally mothers—spend countless hours meeting and consulting with teachers, mental health agencies, court personnel and others to help improve the quality of life for the child with the disability. But siblings of a child with an emotional disability are often left "out of the loop." Often they must figure out on their own or with limited information what is going on with their brother or sister. Sometimes they become fearful, confused or angry about their brother or sister's disability. This fear, anger or confusion can often lead to greater family crisis. If we are, in fact, truly committed to "family involvement" in decision-making, why not involve the whole family in the treatment planning process for children with mental, emotional or behavioral disorders?

Why not include siblings and other significant family members such as fathers, grandparents, aunts and uncles (anyone who is invested in the health of a family member) in the process of defining interventions and treatments? When respite services are being decided upon, why not include a brother's or sister's respite needs as a fundamental family need? When a grandparent is a provider or caretaker (for even part of the time) why not invite them to sit in on the meetings and consultations and make full use of the grandparent's knowledge when designing interventions? We may sometimes find that it is a brother, sister, grandparent or father—either custodial or non-custodial—who brings a critically important perspective to the table.

As professionals and families strive to help improve the quality of life for children with mental, emotional or behavioral disabilities, why not also focus on the quality of life of those closest to the child? Grandparents, sisters, brothers and fathers are family members, too, whose needs and ideas must be included so that the family "as a whole" may begin to heal.

T.W.M.

Editor's Note: *Readers are invited to submit contributions, not to exceed 250 words, for the* Why Not? *column.*

The stress placed on people of culturally diverse backgrounds seems insurmountable. Walking the tightrope between total assimilation and living a cultural life can help to create a "schizophrenic perspective." Golden (1995) noted that a young black man must be "three times as good to get a job an 'average' white man claims on the basis of genes alone" (p. 16). She continued: "The most tenacious folklore of racism and European-defined history defines the black man as a crime against nature. For centuries it was criminal for an African-American to learn to read, to escape slavery to freedom, to compete in business with whites. The legacy of this censorious past is punishment, the Scottsboro Boys, lynchings, a system of justice that metes out different punishments for black and white" (p. 127).

Conclusion.

My sister Margo and I were able to cope. My brother, on the other hand, being the middle child in a family dominated by women with little or no paternal support (or for a variety of other reasons), was unable to cope. The professionals representing the mental health system were quick to suggest that nothing other than drugs could help ameliorate James' problems. The stress that people must deal with because they are African-American or Latino or because they are too fat or not attractive enough or poor is, in part, the culprit. As I read studies about the utilization of mental health services by people who are culturally diverse I nod my head in agreement. James did not gain anything by using the mental health system. In fact, I believe he would have been just about the same if he had never seen a therapist or psychologist. His life really did not matter to them.

Today my brother is an adult in a violent, untrustworthy world. While no longer institutionalized in a state hospital, his state of mind is his institution. I am saddened by so many things. James will never marry someone he loves, will never smile at the first steps or words of his child, will never hold a job, will never enjoy so many of the things that most people take for granted. I am saddened and I am angry that my brother is one of thousands of people with mental illnesses who receive either improper or no treatment—treatment that may have changed their lives for the better. I am saddened and angry when members of this society stand idly by, or turn away when a person with mental illness and no place to live asks for a dime. I am saddened by this lack of respect that we demonstrate for human life. I am saddened by—not just the loss of my brother's functional life—but by the losses of mothers, fathers, sisters, brothers, aunts, uncles, grandparents and children everywhere. I am saddened and angry that we have lost so many lives and seem destined to lose so many more.

TRACY WILLIAMS-MURPHY, B.A., *Project Manager, Increasing Multicultural Parent Involvement Project, Research and Training Center on Family Support and Children's Mental Health.*

Tracy Williams-Murphy

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CHUCK: MY YOUNGER BROTHER

Our family spanned thirteen years, starting with a boy, then five girls, and finally, another boy. We were an active family, playing kickball in the street, camping and picnicking. Until Chuck was born we all experienced good health, except for bouts with chicken pox, measles and an occasional bruise or scrape.

Chuck was the youngest child, a long-awaited boy. He was thin and wrinkled and bald. He received a lot of attention from our parents and his six siblings. Three weeks after he was born, Chuck developed pneumonia and returned to the hospital. All of us worried about the youngest member of our family. His empty bassinet lay nearby, and we were quiet and subdued until he returned.

Chuck has influenced our family deeply since the beginning of his life. Each of the siblings in his or her own way noticed that Chuck was different from the rest of us. He did not speak as soon or walk as well as others. We guarded and watched him more than we would another sibling. We adapted to his frequent tantrums, some by ignoring him, some by yelling at him, and others by rewarding him. He could always get a reaction from one of us.

Although my parents had trials and tribulations with the other six children, Chuck was often the source of disagreement for them. One parent wanted to be more strict, the other more lenient. The opinions of six siblings added to the confusion, so Chuck could usually count on someone to stand up for him. By the time he entered kindergarten, Chuck had definitely earned a reputation in the family.

The years before Chuck entered school were filled with the usual picnics, camping trips and family games. Chuck participated as siblings or parents watched. Chuck often misjudged his sense of safety, so someone was constantly "chasing" him. On one camping trip, our older brother grabbed him as Chuck reached the

edge of a steep hill. We all learned to watch him closely, even when he protested.

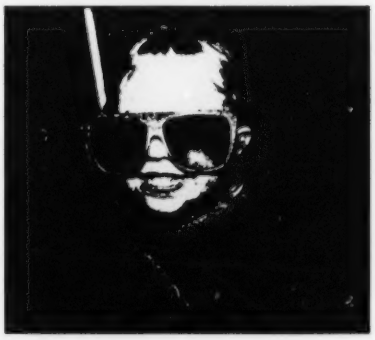
His early school years were challenging, but Chuck made some progress. Unfortunately, he experienced several seizures, and after extensive testing started medication.

It was easy to include Chuck in family activities, because we had power in numbers, and someone would always take a turn watching over him. Eventually it was not critical to watch Chuck all of the time, and it was good to see him become more independent. Chuck became involved in scouting. Two siblings married and moved away, but would often take Chuck and Barbara (the two youngest siblings) on outings with them.

Our family dynamics changed as Chuck finished grade school and started high school. The five older children had made changes, by marrying or moving away from home. Chuck and Barbara remained at home with our parents. By the time Chuck and Barbara were teenagers, several grandchildren had been born. At our frequent family gatherings, new grandchildren played and cried. Grandparents and aunts and uncles enjoyed their new roles and the family felt busy, but comfortable.

During his senior year in high school, Chuck's behavior disrupted our family. He became hostile and combative. He argued constantly with our parents, and several siblings tried to intervene. His dramatic change frustrated and troubled us. Chuck had his first psychotic episode several months later. Our father took him to the hospital after Chuck experienced extreme side effects from his medications.

Nothing in our family is ever simple, because at the same time our mother was in the hospital for surgery on her arm. The next few days the family rallied around our father. He reassured our mother that Chuck responded to medication, and was improving. In reality, Chuck's side effects were harsh, and he recuperated slowly. Siblings visited Chuck and



"digested" the situation.

The diagnosis of schizophrenia took even longer to digest. Our mother had always taught us to look things up in the medical book, so we headed for the closest medical book to find the answers for ourselves. Some of Chuck's recent behavior made more sense after reading about schizophrenia. The most difficult part of the reading explained that schizophrenia is a very long-term illness. Chuck was still in the hospital, adjusting to medication. He lost weight, walked slowly, and stopped at every water fountain to drink. Meanwhile, all of us tried to understand what was happening to Chuck.

Chuck's first hospitalization taxed everyone in the family. Chuck experienced difficulty with several medications, which lengthened his stay. Doctors changed almost daily, so my parents did not get consistent information. Chuck was also over eighteen at the time, so they received limited information. Chuck's appearance changed and he looked very old. The doctor explained that Chuck's experience was similar to someone who had just had major surgery. He gradually recuperated as we watched and learned.

Through the next fifteen years, several major changes occurred in our family. New grandchildren, a new business, four divorces, Dad's retirement, three grandchildren's high school graduations, and two major illnesses. Throughout that fifteen years Chuck has been hospitalized many times. I attended a commitment hearing and watched my brother's bizarre behavior. I heard my mother read from her journal and give testimony that helped get Chuck committed. During Chuck's various hospitalizations, several siblings visited, and some did not.

We accepted Chuck's childhood tantrums and odd behavior because they felt relatively harmless. Bizarre or controversial behavior in an adult is unpredictable and frightens us. Chuck's first hospitalization shocked and worried us. We thought he might not come out of his reaction to the strong medications. We thought he might be like that forever. Now that we have watched him behave noncooperatively in group living situations, and have seen him respond aggressively to case workers, we are cautious and angry.

Each sibling in our family has reacted to Chuck's illness differently. One remains distant, but angry. Another stays strongly focused on her own family. Still another is very busy, but always involved with Chuck. One prefers individual contact with parents instead of the constant addition of Chuck. One is very loyal to her parents and tolerant of Chuck. Another is fearful and avoids family functions. Chuck's expectations of his siblings and parents remain high.

As our family expands, we allow the opinions of others to influence us. Spouses, friends and children alter our views of Chuck and our parents. Chuck's last hospitalization lasted one year. Our parents traveled extensively and enjoyed the freedom. Their travels continue, but their weekends are often limited because Chuck relies on them for leisure activities, food and comfort. Siblings involved with their own families seldom include Chuck individually in their activities. Family gatherings provide the social contact Chuck enjoys. Recently the number of outings has decreased because one or two siblings and their families might stay away. This past Christmas one family chose to avoid the gathering at our parents' home. Many of us were angry at the family who stayed away. We have suddenly developed strong opinions about Chuck's involvement with our family.

Should we protect our children, or should we include Chuck? Many siblings think we can do both. Some are fearful, since Chuck has been aggressive and inappropriate in the past. Some siblings are not willing to gamble that Chuck's most recent hospitalization has been the most helpful and that his behavior changed.

Through all of the sibling debate, our parents remain loyal to Chuck. The stigma of Chuck's mental illness is attached mostly to Chuck and to our parents, since siblings can choose to become detached. As our parents age, we become more concerned about their retirement years. Both parents support and participate in the National Alliance for the Mentally Ill. They know and work with Chuck's mental health professionals. Siblings generally ask about recent developments with Chuck, but few interact personally with Chuck unless he is in our parents' home.

We will undoubtedly begin our family gatherings again, but we will not worry about who does or does not participate. Those who do not come will miss a fun time. Our strong history of weekend picnics and family birthday events will continue, with a new awareness. We have endured fifteen years of mental illness. We will change as the course of the illness changes. Just as we watched Chuck as a young child, we will watch him now to make sure that he and the rest of us are safe.

Each of us wrestles with Chuck's schizophrenia separately; it is sometimes a delicate issue for us, because it is painful. Chuck missed several summers because hospitalizations kept him away from activities and carefree times. His life is different from ours, and we sometimes do not comprehend it. We are all part of a vibrant, active family and Chuck enjoys it. Our challenge is to accept him and to understand our roles as siblings to Chuck and children to our parents.

Susan Tingley

SUSAN TINGLEY
Portland, Oregon

FAMILY PERSPECTIVE

I NEVER WANTED TO LIVE IN NEW YORK CITY

When I was pregnant with my son, I dreamed, as mothers do, about what our life would be like. I saw us living in a sleepy little town, where life was slow and predictable. I would know almost everyone and they would know me; and people would say, "Isn't she a good mother!"

I like quiet things like soft music, a silent snowfall and so I saw our days as serene, mild, and sunny. We would read books, rock, sing lullabies, and share gentle hugs. Our street of life would be peaceful with little traffic or noise—no sirens here!

But when my son was born, it was as if I'd emerged in New York City. Every day, every hour, was a screeching, horn-blowing nightmare. It was howling, sleepless nights with a baby that—like New York City—never seemed to sleep, never paused. There were many gray and stormy days. No interest in rocking and scant patience for lullabies.

My child: restless, brilliant, always seeking the bright lights, the hustle, the noise, things that moved. He had places to go. There were no quiet walks through silent snowfalls—but shrieking, running, falling, crying, bursting into the snowy world as if he could capture it all. I couldn't slow him down, to make him see the kind of town I wanted. All he wanted was New York City. Friends, family and neighbors shook their heads and I was sure they were saying, "Not a good mother. She must be doing something wrong."

Then came teachers, new doctors, and strangers who wanted to hear my story. I met people I never wanted to meet. I went to meetings, conferences, lectures, to learn about this, learn about that. Find a name, a label—wait—is it this, or is it that?

As I lived through the great highs, the note that said, "He behaved well today," I survived the lows, "Call me. A terrible day." I began to understand dashing headlong through the snow when I felt I couldn't get through another day.

The strangers I've met—other mothers who live in this city too—have become my best friends now. They are friends of the heart. Sometimes I see a friend who lives in that sleepy little town and we have little to say to one another. She seems to wonder why I live in New York City instead of in her sleepy little town. I don't tell her that sometimes late at night I think of that town where I thought I would live, but it never really existed for me.

Reality is living life with a sharpened edge—never knowing where my son will take me, often to see things I'd never see on my own. Real for me is living with bright lights, sirens, endless traffic. It is seeing the tallest towers in the world and wondering how I'll ever get over them. Real is living with a hyperactive child. And I've changed, changed so much in so many ways that when I dream, I dream of New York City.

Marilyn Churchill,
Green Bay, Wisconsin.

Editor's Note: *Parents are invited to submit contributions, not to exceed 250 words, for the* Parents' Perspective *column.*

MY SON TAUGHT ME TO KEEP FIGHTING AND TO KEEP MY HEAD RAISED HIGH

When my son was hospitalized and diagnosed with a mental illness, I was embarrassed. I felt I had failed as a parent and father as well as being a poor role model for my church congregation as their pastor.

However, my congregation rallied around my family and me. One couple visited us when our son was hospitalized and helped us as a family work through our pain. When our son came home after his second hospitalization, three families offered to watch him for a few hours so my wife and I could have some free time. It was very draining to be the caregiver of a child diagnosed with bi-polar illness and have no breaks from our caregiving responsibilities.

It was very difficult and frustrating to watch our son deteriorate. As he deteriorated, our dreams for him shattered. At a young age my son had been tested through the schools. His test scores were very high. At one point we were told, "You've got a genius." My son began reading at about the age of three and one-half and could carry on wonderful conversations. We were so excited about his potential!

After my son's first hospitalization we were told that he would probably not complete high school. We could forget about college completely. How devastating! My question was, "What about his potential? Did someone make a mistake?"

With all of this crashing down upon me, what has sustained me has been my personal religious faith and my local support group, the Mid-Valley Alliance for the Mentally Ill.

This support group has helped me work through my feelings of embarrassment, frustration, and anger in a healthy manner. It has also empowered me to be an advocate working toward better understanding of mental illness, working to obtain better services for my son and others in a system that is archaic and dehumanizing. This had led me to speak to elected officials, the "faith community", schools, civic groups and others. My goal is to inform these individuals and groups about mental illness and how they can offer solutions and services to those with a mental illness and their family members.

As a Presbyterian minister I pastored for many years in the states of California, Washington and Oregon. Recently, I resigned my position and started Compassion Ministries. I am attempting to educate the faith community about mental illness, to eradicate the stigma associated with this disease, and to help the faith community learn how they can reach out to people with mental illnesses and to their families.

I must confess, however, that I often wonder "when the other shoe will drop." I am fearful of another episode or crisis with my son's illness as it rears its ugly head. Yet, I have many resources to draw upon: my religious faith, the Alliance for the Mentally Ill, education about the illness, my church, and my wife. Had our son not come into our home, I would have never been exposed to such a variety of folks from various walks of life who have so much empathy and who have offered so much support. My son has taught me to never give up, keep fighting and keep my head up. For this, I thank him.

Mike Rinkin

MIKE RINKIN
Albany, Oregon

NEW CHILDREN'S MENTAL HEALTH PUBLICATIONS AVAILABLE

From Case Management to Service Coordination for Children With Emotional, Behavioral, or Mental Disorders: Building on Family Strengths details the national shift to delivering coordinated, family-centered care. The focus throughout this newly published book is upon building rapport with each family, closely involving families in decision-making about their children's care, and providing community-based services in the home, at school and in recreational environments. This first volume in a new book series *Systems of Care for Children's Mental Health* addresses a range of service coordination issues including, among others: (1) initiating case management services; (2) coordinating interagency efforts; (3) financing under Medicaid and through private insurers and managed care organizations; (4) gathering data based on outcomes and computerizing records to increase efficiency; (5) developing a curriculum and goals for training; and (6) emphasizing the importance of the family's role in providing care. This volume is edited by Barbara J. Friesen, Ph.D., Director, Research and Training Center on Family Support and Children's Mental Health, and Professor, Graduate School of Social Work, Portland State University, Portland, Oregon and John Poertner, D.S.W., Professor, School of Social Welfare, University of Illinois, Urbana, formerly at University of Kansas, Lawrence. For ordering information contact: Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, Maryland 21285-0624; voice: (800) 638-3775; fax: (410) 337-8539.

Making Medicaid Work to Fund Intensive Community Services for Children with Serious Emotional Disturbance:

An Advocacy Guide to Financing Key Components of a Comprehensive State System of Care offers a summary of the federal rules on EPSDT (Early and Periodic Screening, Diagnosis and Treatment) services as well as a discussion of targeted case management as an optional Medicaid service. Additional topics include: (a) a description of home- and community-based services Medicaid waivers that permit states to offer a variety of services within the community for children who would otherwise require institutional care; (b) freedom of choice waivers to provide care through prepaid, capitated arrangements; and (c) a summary of states' use of Medicaid to fund intensive community services for children with serious mental, emotional or behavioral disorders. For ordering information contact: Bazelon Center for Mental Health Law, 1101 Fifteenth Street N.W., Suite 1212, Washington, D.C. 20005; (202) 467-5730; TDD: (202) 467-4232.

Components of a System of Care: What Does the Research Say? reviews the literature on the effectiveness of the components in a system of care for children with serious mental health problems. This 1994 review of recent research literature addresses the following eight components in a system of care for children: residential care, outpatient psychotherapy, day treatment services, family preservation services, therapeutic foster care, crisis and emergency services, case management/individualized care, and family support services. For ordering information contact: Research and Training Center for Children's Mental Health, Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Blvd., Tampa, Florida 33612; (813) 974-4661.

Doing things differently: Issues and options for creating comprehensive school-linked services for children and youth with emotional or behavioral disorders, a recent publication through the Center for Policy Options in Special Education, promotes awareness of the issues involved in creating comprehensive, flexible educational programs for students with emotional or behavioral disorders. A discussion of specific problems associated with services for children and youth with emotional or behavioral disorders includes the following topical areas: unserved students, cultural bias, failing programs, and a lack of comprehensive educational programs. Critical education issues are identified and policy options are explored. For ordering information contact: Center for Policy Options in Special Education, Institute for the Study of Exceptional Children and Youth, University of Maryland at College Park, College Park, Maryland 20742-1161; (301) 405-6509.

Resources for Staffing Systems of Care for Children With Emotional Disorders and Their Families is the result of a national survey funded by the Center for Mental Health Services, United States Department of Health and Human Services, to begin to identify strategies and resources for recruiting, retaining, training and developing a workforce to delivery community-based, family-focused services to children and their families within the context of an interagency system of care. For ordering information contact: National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center, 3307 M Street, N.W., Washington, D.C. 20007-3935; voice: (202) 687-5000; fax: (202) 687-1954.

Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood: 0-3 provides a comprehensive framework for diagnosing emotional and developmental problems in the first three years of life. This volume identifies and describes disorders not addressed in other classification systems and the earliest manifestations of problems described in other systems for older children and adults. Infants' and toddlers' reactions to trauma, disturbances in affect, difficulties in regulation of mood and behavior, and problems in relationship and communication patterns are some of the types of disorders addressed. For ordering information contact: Zero to Three/National Center for Clinical Infant Programs, 2000 14th Street North, Suite 380, Arlington, Virginia 22201; voice: (800) 899-4301 or (703) 528-4300.

Where Can We Turn? A Parent's Guide to Evaluating Treatment Programs for Troubled Youth assists parents in their efforts to research treatment programs for their sons and daughters. The topics addressed include identifying a program's treatment philosophy, how the program deals with youth running away from the program, understanding program costs and insurance coverage, length of stay, admission procedures, and receiving school credits. The guide also includes a scoring sheet for parents so that they can evaluate a program before enrolling their child. For ordering information contact: Jefferson Resource Institute, Inc., P.O. Box 211418, Salt Lake City, Utah 84121-8418; (801) 944-1174.

1996 NAMI-CAN SUMMER 1996 MEETING

The 1996 National Alliance for the Mentally Ill's (NAMI) annual convention will be held at the Opryland Hotel in Nashville, Tennessee July 6-9, 1996. A special pre-convention Children and Adolescents' Network (CAN) session scheduled for July 5th will focus on the needs and interests of parents whose children have mental, emotional or behavioral disorders. Additional sessions of interest to parents will be presented throughout the four-day convention. For more information on the convention please contact: Convention Department, National Alliance for the Mentally Ill, 200 N. Glebe Road, Suite 1015, Arlington, Virginia 22203-3754; voice: (703) 524-7600; fax: (703) 524-9094.

BUILDING ON FAMILY STRENGTHS CONFERENCE FEATURES RESEARCH AND INNOVATIVE PROGRAMS

The Research and Training Center on Family Support and Children's Mental Health hosted the second annual conference, *Building on Family Strengths: Research and Programs in Support of Children and Their Families*, in Portland, Oregon on June 1-3, 1995. More than 400 family members, researchers, educators, service providers, advocates and policymakers attended. The conference was designed to provide a forum in which to examine and disseminate state-of-the-art research findings and issues of family support and family-centered services and to highlight family participation in the research process. The conference was also a forum in which participants could interact and exchange information on a wide range of family research issues.

Four major themes were addressed through paper, symposia and poster presentations: developments in family research methods, family member/consumer involvement in research, family support, and family diversity. The majority of workshop sessions addressed both research and program issues with topics such as system barriers to services, family roles in designing and implementing policy, and family-centered approaches to research and evaluation. Several workshops discussed aspects of diversity by outlining strategies for family involvement, and highlighting strengths of families and communities as well as natural support systems.

More than twenty family members and professionals presented visual descriptions of their research in a lively poster session. Topics of poster presentations ranged from an evaluation of a family support project to wraparound training for parents. In addition, special interest groups met each evening to consider strengths and challenges for local programs and research projects involving family members.

Family members and professionals joined together to present many of the workshops and two of the plenary sessions during three meeting days in Portland. Parent stipends were awarded to approximately fifty participants. Stipends covered conference-related expenses such as air fare, lodging, meals, registration fees or child care.

The initial keynote was given by Karl Dennis, executive director of Kaleidoscope, Inc. in Chicago. Always a popular speaker with both parents and professionals, Mr. Dennis discussed the implications of wraparound services for children, their families, and the service providers and communities around them.

Dr. Peter Jensen, chief of the Child and Adolescent Disorders Research Branch of the National Institute of Mental Health, spoke at the second plenary session. He described advances in research that have the potential to benefit children and their families. Dr. Jensen also acknowledged gaps in knowledge and understanding of childhood disorders by clinicians and researchers and invited family members to consider themselves as experts about their own children.

A luncheon plenary on the topic of family-centered, culturally competent systems of care included dynamic presentations by Velva Spriggs and Janice Hutchinson. Ms. Spriggs is the director of Planning and System Development Programs in the Child, Adolescent and Family Branch of the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services. She discussed the need for all parties in the treatment of children to confront and eliminate racism in communication, service delivery and policymaking. Dr. Hutchinson, acting administrator of the Child and Youth Services Administration, District of Columbia, used brief video segments about the district's outreach programs to illustrate the necessity for innovative thinking in order to deliver mental health and other services to children wherever they are.

The Oregon Family Support Network co-sponsored an evening reception designed as a forum for parents, family members, caregivers, advocates and professionals to meet and exchange ideas and information. This program featured introductions of professionals and family members from the twenty-two Service Initiative Sites and leaders of the twenty-eight Family Network Grants. Other sponsors included the Research and Training Center on Family Support and Children's Mental Health, the Federation of Fami-

MARK YOUR CALENDARS

Building on Family Strengths: Research, Advocacy & Partnership in Support of Children and Their Families

Conference Dates:
April 11-13, 1996
Location: Hilton Hotel
Portland, Oregon

For Additional Information :
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lies for Children's Mental Health, and the Department of Mental Hygiene at Johns Hopkins University.

The conference concluded with a panel describing "Positive Examples of Researcher/Family Collaboration." The panelists were Mary Evans of the New York State Office of Mental Health; Valerie King of the Citizens' Committee for Children of New York; Philip Leaf from Johns Hopkins University Department of Mental Hygiene; Susan Tager, Familes Involved Together, Baltimore;Yvette Nazario of the Bronx Parent Resource Center; and Mary Telesford, Annie E. Casey Foundation Site Advisor for the Federation of Families for Children's Mental Health.

The Building on Family Strengths Conference was co-sponsored by the Research and Training Center on Family Support and Children's Mental Health; the National Institute on Disability and Rehabilitation Research, U.S. Department of Education; the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services; the Annie E. Casey Foundation's Urban Children's Mental Health Initiative; the Department of Mental Hygiene, Johns Hopkins University; the Federation of Families for Children's Mental Health; and the Oregon Family Support Network.

Conference proceedings, including transcripts of plenary sessions and summaries of workshop presentations, will be available.

For additional information contact: Kaye Exo, M.S.W., conference coordinator, Research and Training Center on Family Support and Children's Mental Health, P.O. Box 751, Portland, Oregon 97207-0751; Telephone: (503) 725-5558; TDD: (503) 725-4165; Fax: (503) 725-4180; E-Mail: kje@rri.pdx.edu

CONFERENCE ATTENDEES

Craig Ann Heflinger, Vanderbilt University, Nashville, Tennessee

Harold Briggs, Research and Training Center on Family Support & Children's Mental Health

Jean Kruzich, University of Washington, Seattle and Research & Training Center, Portland

Ann May, Families CAN, Raleigh, North Carolina

Melvin Delgado, Boston University, Boston, Massachusetts

Susan Yuan, University of Vermont, Burlington, Vermont

Martha Matthews, National Center for Youth Law, San Francisco, California

Debi Elliott (left), Portland State University and Marilyn McManus, Research & Training Center

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